

Preparing for Flu Season

A new and very different influenza virus called "2009 H1N1" (swine) flu has emerged and is causing illness in people worldwide. Scientists believe the new H1N1 virus will cause illness, hospital stays and deaths in the United States over the coming months.

This flu season may be more severe than usual because of the new H1N1 virus. This means that more people may become sick and more people may get seriously sick. Also, regular flu viruses will continue to spread and cause illness too.

People with certain health conditions may face special medical

challenges during flu season. These health conditions include:

- Neurological disorders (including nervous system, brain or spinal cord)
- Neuromuscular disorders (including muscular dystrophy and multiple sclerosis)
- Pregnancy
- Cancer
- Blood disorders [including asthma or chronic obstructive disease (COPD)]

- Diabetes
- Heart disease
- Kidney disorders
- Liver disorders
- People with weakened immune systems (including people with AIDS or those who are receiving chemotherapy)

It's important to remember that people who have one of more of the conditions listed above can have a more severe illness from See **Flu Season** on page 7

New Voice in the Little Rock Office

You may hear a new voice answering the phones when you call the Little Rock ASCC Case Management office. Marie Campbell has recently joined the office providing support to Case Managers Doug Fish and Dee Welsh. She began her duties in September and has quickly adapted to the procedures and daily routine of the office.

Marie has a Bachelors degree in Elementary Education/Business and has a strong background in customer service with experience working in a medical setting. "We wisely recruited her to assist with the Spinal Courier newsletter as a member of our newsletter staff," commented Client Services Administrator Patti Rogers.



Marie Campbell

Marie and her husband, Jody, live in East End with their three "furry kids," Ebony, Daisy and Henry. When not playing with the dogs, Marie likes to spend her free time reading a good mystery. Her favorite author is Mary Higgins Clark.

Please join us in welcoming Marie to the ASCC staff.

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SPINAL COURIER

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With Thanks

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ASCC accepts tax-deductible donations. Contributions are used to assist our clients through purchases of equipment and educational resources.

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AR Spinal Cord Commission
1501 N. University, Suite 470
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From the Director

Everywhere you look there is discussion about healthcare reform! For, against, afraid, angry, virtually everyone has an opinion. It is apparent that all of us are concerned about our health and our access to health care. I know I am. Of course, I keep trying to figure out how it affects me personally and also all of you – whether you have Medicaid, Medicare, personal insurance, or no coverage at all. Over the years, I have certainly seen spinal cord disabilities financially break families! Some of the concepts sound positive to me – there seems to be support for not allowing denial of insurance for preexisting conditions. That impacts a lot of us. An affordable option for folks to purchase insurance and requiring Medicare to take bids on medications in order to lower the end-user cost make sense to me too! At least one proposal I've seen removes the 2-year waiting period for Medicare after disability determination and expands the scope of Medicaid waivers. I like those. I'm not expecting a plan that includes everything I think we need, but I hope we get close. I'm thinking that this year's reform will be the beginning not the end of this legislation! I hope so. I urge you to listen and make your own decisions. Then let your Congressman and Senators know what you think and what you need! I think they will be listening!

Speaking of new healthcare options, I got to tour a new option in Arkansas on a trip to Springdale last month. As far as I know Victory Walk, Inc is the first community program to offer activity-based therapy to folks with spinal cord injuries in our state. When a family member sustained quadriplegia, the Lemke family looked for a resource and not finding it in our state, they created it themselves. This fledgling, not-for-profit organization has seen some great physical progress in those who participate in the program on a regular basis. Activity-based therapy (think a combination between athletic training and physical therapy using accessible equipment) isn't for everyone, but it can have amazing impact if you are willing to commit. If you are interested, you might want to contact them at **www.VictoryWalkInc.com**.

Enjoy the beautiful Fall and don't forget to get your flu shot!

Cheryl L. Vines

Book Explores Little Talked about Subject

I recently read the book *(W)hole*, written by the Arkansas author Ruth Madison (available on Amazon.com).

Although this is essentially a love story, it also bares the secret fetish of being attracted to the disabled. I know I must not be alone in all my years in a wheelchair, in having known someone with this unusual attraction.

This book brings it into the open and explains it's many sides. There are probably other readers that have been curious about this little known subject.

I would rate this book PG. An interesting fall read.

Karen L. Percz

Spinal Cord Injury Conference Well Attended

Over 225 people came together on August 21st at Pulaski Technical College to make the ASCC *Living Well with Spinal Cord Injury* conference at huge success.

Participants listened to informative speakers, visited with vendors about new equipment, viewed or took part in exhibits, enjoyed a delicious box lunch, renewed old acquaintances and made new friends.

ASCC clients also learned about emergency preparedness and received a backpack of supplies courtesy of Partners for Inclusive Communities.

Pictured below are a few of the conference participants and door prize winners.



Sherrice Smith tries out a hand-pedal bike.



Dr. Stanley Ducharme spoke about sexuality after spinal cord injury.



Janet Pool won a 75 piece socket set!



Victory Walk Inc. exhibit.



Cheryl Vines congratulates Billy Altom on winning the grand prize of a Quickie manual wheelchair.



Chris Cross won a \$25 gift card.



Mary Badger won a seat cushion.



Joe Canose of the Christopher & Dana Reeve Foundation spoke about paralysis in the U.S.



Disability Rights Center exhibit.



Elvin Whitehead won a \$50 gift card.

Living Well with SCI: by the Numbers

By Tom Kiser, M.D., ASCC Medical Director



ASCC Medical Director Tom Kiser, M.D.

At the annual spinal cord injury conference in Little Rock this year, the focus was “Living Well with Spinal Cord Injury.” I was asked to give a brief presentation on my recommendations for “Living Well” from the medical and rehabilitation perspective, prior to a panel discussion on the same topic.

Both the presentation and panel discussion was well received with good questions from the audience.

Many attendees requested a list of the ten items I presented, so we decided to publish the list, here, in the Courier and provide a more in-depth discussion of each recommendation. Due to Courier space constraints we’re presenting only one or two at a time in order to give justice to each recommendation. So here are numbers 10 and 9 of the “Ten Things I encourage my patients to do!” I will be working toward number 1 in future Courier articles:

Number 10: Pain Management

- Minimize the use of narcotics.
- Know the difference between neuropathic pain (burning, electrical, and hard to describe pain) and musculoskeletal pain (above level of injury pain).
- Use the lowest dose of pain medication that is effective.

Pain after a spinal cord injury is very common and is usefully classified in the following manner: above level pain, at level pain and below level pain.

If your pain is above the level of your spinal cord injury, where you have normal sensation and motor function, the pain is usually due to the routine aches and pains of life. Due to your spinal cord injury, your upper extremities are used for a lot more activities (such as wheelchair pushing, transfers, and overhead reaching, just to name a few), than were required of them prior to your spinal cord injury. Therefore, your risk of shoulder problems, muscle aches, and pinched nerves are more pronounced. This pain can usually be managed with modifications to your activity and an assessment of your wheelchair use, transfer technique, and daily routine. We can

Pain after SCI is very common . . .

then address the problem areas and provide the necessary medication and therapy to address the aches and pains you are feeling. Narcotic medication for treatment of this type of pain is rarely warranted, and if used should be limited in dose and duration.

At level pain and below level of injury pain are in areas where your spinal cord injury affects the interpretation of sensory signals from your body. We call this type of pain by several names: central pain, neuropathic pain, and deafferentation (due to loss of sensory input, also known as afferent signals) pain. This type of pain is very difficult to treat, and until recently, we had limited medications and treatment methods for this pain. In the past, we relied heavily on tricyclic antidepressants (amitriptyline,

imipramine, etc.) and the TENS (transcutaneous electrical nerve stimulation) unit to modulate and decrease the pain. Recently new medications such as gabapentin, duloxetine, and pregabalin have been added. In general, all these medications help, but in my experience none of them provide total relief. Because some of you (and I would say a very small percentage) have unsatisfactory relief of your neuropathic pain, even with the use of these medications, the use of narcotics is invariably proposed.

I advise against the use of narcotics for several reasons: 1. Narcotics will affect your bowels and your bowel program, and we often have to add another medication to counteract the side effects of the narcotics; 2. Narcotics have addictive potential and a certain population of individuals are very susceptible to this (and if narcotics make you feel exceptionally good, you are definitely at risk); 3. Narcotics lose their potency with chronic use. This phenomena is called habituation. To achieve the same level of pain relief, higher and higher doses of narcotics are required, which lead to more and more side effects (constipation, respiratory depression and mental confusion). I have had several patients who started taking a reasonable dose of narcotics and eventually were on

See **Living Well** on page 5

Let's Make Arkansas Water Recreation Areas More Accessible!

The Arkansas Game and Fish Commission is requesting public input on ways to increase accessibility of boating access sites and public fishing piers in the state's recreation areas.

Suggestions are requested not only from people with limited mobility or use a wheelchair but also from people with other limitations, such as the elderly, those with visual or hearing impairments.

Suggestions should be specific as possible and identify obstacles and barriers that you or others have encountered in visiting state recreation areas. Send your ideas to:

Dale Gunter, Chief Counsel Engineer & Real Estate, #2 Natural Resources Drive, Little Rock AR 72205

You may also email Mr. Gunter at jdgunter@agfc.state.ar.us

Living Well

Continued from page 4

high doses of narcotics with more side effects and the same pain they started with in the first place.

Therefore for my patients who want to run the risks of using narcotics to manage their pain, I recommend the following protocol. Only use narcotics rarely (every third day or weekly), only when you are at your wits ends, and only when nothing else is working. A low dose of pain medication will often allow you to sleep or change your mental focus. This avoids habituation, which leads to ever higher doses and ever worsening side effects, and provides you a back up medication to use when nothing else seems to be helping.

Number 9: Vaccinations

Vaccinations for Tetraplegics and High level (T2-T6) paraplegics with a weak cough.

- Annual flu vaccination
- Pneumococcal vaccination at least once and again at age 65
- Diphtheria and Tetanus at least every 10 years.

Preventing influenza and pneumococcal pneumonia can save your life. If you have decreased respiratory function due to a cervical or a high thoracic spinal cord injury as evidenced by a weak cough, your ability to fight off pulmonary infection is markedly reduced. We also know that the immune system of an individual with a spinal cord injury is not as robust as someone's without a spinal cord injury, so any preventative measures you take to increase your immunity and resistance to infection are good and prudent ideas. So, make the yearly visit to your doctor for an annual flu shot a habit!

The pneumococcal vaccine provides increased immunity to a particularly potent bacterium which can lead to a severe pneumonia. How often this vaccination is needed is not clear, but a vaccination shortly after your injury and again when you are 65 years old would be the minimum. Every 10 years would be aggressive in my mind unless you are at extreme risk. Risk factors include chronic ventilator use and medical history of a lung disease, or smoking. The diphtheria and tetanus (DPT) injection is recommended every 10 years for the general population and also for persons with SCI.

Living Well with SCI will continue in the next issue of the Spinal Courier. Editor.

Mayo Clinic SCI Guide Now Available

Nearly everyone has heard of the Mayo Clinic. They are famous for their quality of care and finding medical solutions to difficult problems. Their website, mayo-clinic.com provides easy-to-read, reliable medical information from acne to zoster!

This Spring, the *Mayo Clinic Guide to Living with a Spinal Cord Injury* was published. It is an interdisciplinary resource, written by members of the clinic's rehabilitation team, who have treated folks with SCI for over 40 years.

The book is divided into five chapters with each divided into sections. For example, Chapter II, Managing Changes to Your Body, includes sections on respiratory management, bowel, bladder, skin, muscles, bones and circulation. It also includes good illustrations, tables and a glossary.

This is an excellent, comprehensive resource on life with SCI. The guide may be checked out from the ASCC McCluer Resource Library at **800-459-1517** (ask for Resource Library) or purchased from Demos Health publications.

Christmas is Coming . . .

Mark your calendars now for the Spina Bifida Support Group of Arkansas Annual Christmas Party. Individuals who live with spina bifida and their families are welcome. The party will be held at Camp Aldersgate, 2000 Aldersgate Rd., Little Rock, AR.

This year's party is scheduled for **Sunday, December 13th from 2:00 to 4:00 p.m.** Activities will include music, games, fellowship, Chef Garry's great cooking and a visit from *You Know Who!* Additional information will be sent out in November. If you have questions, contact Vicki Rucker at **501- 978-7222**.

Up Close and Personal: John Wyrick

This is the fourth in a series of articles profiling the ASCC Commissioners.



John Wyrick was appointed to the Arkansas Spinal Cord Commission by former Governor Mike Huckabee on January 13, 2003 and will serve until January, 2013.

A long-time resident of west Pulaski county, John has been a cattleman for many years. In August of 1997, he was trimming a tree in a pasture when it swung back and knocked him 15 feet to the ground. He was immediately rendered a T12 paraplegic. After his acute care, John went to Craig Hospital in Denver, Colorado for his SCI rehabilitation. He credits the staff there with helping him to accommodate, physically and emotionally, to his disability and learn about life with SCI.

After rehabilitation, John returned immediately to his family business, Esquire Marble, and continues working there today. John and his wife Donna are advocates for wheelchair accessibility. When they find an inaccessible restroom from hospitals to hotels, they try to educate the owners to what accessibility means. Over the years they have found themselves in some very difficult accommodations, often when they were told the venue was accessible.

John is an expert trap shooter. He is a member of a local trapshoot-

ing club and travels to trap shoots around the region. He recently returned from the Pensacola, Florida wedding of his youngest son. Both of his sons are presently serving in the United States Navy.

"We are very lucky to have someone with John's business acumen

on our Commission," said ASCC Executive Director Cheryl Vines, "As a business man, he sees issues from several different perspectives and helps us in our planning and community efforts.

John is a man of few words, but when he speaks we listen!"

PROFILE:

Date And Place Of Birth: September 28, 1947 McKinney, TX.

Family Members: Wife Donna, five children: sons Jared and Drew and daughters Kandy, Amanda and Elise; eight grandchildren—aged 13 months (twins) to 23 years.

If I Did Not Live In Arkansas, I Would Want To Be: Any place in Texas.

My Favorite Meal Is: Steak and potatoes.

My Favorite Movie Is: *The Searchers* starring John Wayne.

My Favorite Song Is: Anything George Strait sings.

Last Good Book I Read: *Saving Private Ryan*.

My Favorite Hobbies Are: Trap shooting.

My Favorite Saying: Don't really have one.

The Best Advice I Ever Received Was: A guy at Craig Hospital when I was doing my rehab there kept telling me, "Don't give up, you will be able to do it."

My Advice To The Newly Injured: There are worst things that can happen to you.

I Knew I Was Grown Up When: I had my first child!

The One Thing I Always Wanted To Do But Have Never Had The Chance Was: Go on a cattle drive out west.

One Word that Sums Me Up: Steady.

Flu Season

Continued from page 1

any influenza infection, including illness with the new H1N1 virus. Unless your health care provider says not to, keep taking your medication even if you become sick with the flu.

If you have one of these health conditions and you develop flu-like symptoms, contact your health care provider or seek medical care.

Flu-like symptoms (including the symptoms of the new H1N1 flu) include fever, cough, sore throat, runny or stuffy nose, body aches, headaches, chills, and fatigue. Some people also may have diarrhea and vomiting.

If you have one of the health conditions listed, during a flu outbreak you should:

- Seek medical attention if you have a fever and symptoms of the flu.
- Limit contact with crowds and avoid crowded places. If you can't avoid crowded settings, consider wearing a facemask or respirator to decrease your chances of getting infected. Be careful not to touch your face. Wash your hands often.
- It is estimated that staying at least six feet away from a person who sneezes or coughs may be a safe distance.
- Talk with your doctor about having a two-week supply of medication.
- Keep the name, phone number, and office address of your doctor or health care provider with you at all times. Find out the best way to communicate with your doctor.
- Get a written record of the kind of chronic disease(s) you

have and the treatment you are receiving. Keep this information with you at all times.

- Prepare a typed or printed list of all medications usually taken and the times of the day they are taken. Also include necessary medical supplies or equipment such as syringes, strips, lancets if you have diabetes, or oxygen if you have COPD.
- Determine how you will access ongoing medical care such as chemotherapy or radiation therapy. Ask your health care provider if they have a plan to deal with a severe flu outbreak (including new H1N1 flu).
- If you use medications for your condition, continue taking them even if you become sick with the flu, unless your doctor or health care provider says otherwise.
- Be alert to changes in your breathing especially if you have heart failure, congestive heart disease or COPD. Promptly report changes to your doctor or health care provider.
- Inform family members or close friends of your medical condition.

For more information, visit www.cdc.gov/h1n1flu

ASCC Message Board Keeps Rollin' Along

The ASCC online Message Board is a way for clients to keep in contact with one another and share common concerns and experiences. In its second year of operation, the Message Board enjoys an increased membership. Access the site by logging on to ascc.websitetoolbox.com.



Grant Marshall.

Governor Beebe Appoints Grant Marshall to Technology Committee

Grant Marshall of Magnolia was recently appointed by Governor Mike Beebe to the Technology Equipment Revolving Loan Fund (TERLF) Committee for a term expiring June 30, 2012.

Mr. Marshall graduated from Southern Arkansas University in 1981 with a BA degree in History and Mass Communications. After graduation, Grant was employed as a News Director for KVMZ and KZHE for over 10 years. Grant has also worked as the Public Address Announcer for Southern Arkansas University for 27 years. During 12 years of that time he was also the Public Address Announcer for Stamps High School Football and four years for Magnolia High School Football.

Grant is the son of Don and Katie Marshall, both retired professors of Southern Arkansas University.

The TERLF committee provides low-interest loans to Arkansans with disabilities to purchase assistive technology equipment and services in order to help them become more independent and productive members of the community. Mr. Marshall, living with spina bifida, brings a wealth of experience and insight to his new assignment.

Morgan Love Receives Scholarship from Governor Beebe

Morgan Love, who lives with spina bifida, was one of twenty recipients of the Governor’s Commission on People with Disabilities academic scholarships. Governor Mike Beebe presented the award to Morgan at an event at the Governor’s Mansion on July 14th, 2009. Morgan graduated from Sheridan High School in May. He is attending Henderson State University this fall, where he plans to study history. “It was a pleasure to see Morgan receive this well deserved honor,” noted ASCC Executive Director Cheryl Vines who attended the event. “I know his parents are very proud of him, and I certainly am too!”



Morgan Love is presented with an award of Excellence recognizing his receipt of an academic scholarship.

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